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Shrikant Atreya^{1*} and Purushottam A Giri²

¹Consultant in Palliative Medicine, Department of Palliative Care and Psycho oncology, Tata Medical Center, Major Arterial Road, Newtown, Kolkata, West Bengal, India

²Professor, Department of Community Medicine, IIMSR Medical College, Badnapur, Jalna, Maharashtra, India

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***Corresponding author:** Dr. Shrikant Atreya, Consultant, Palliative Medicine, Department of Palliative Care and Psycho oncology, Tata Medical Center, Major Arterial Road, Newtown, Kolkata 700160, India, E-mail: atreyashrikant@gmail.com

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Short Communication

Palliative Care for Cancer: A Public Health Challenge in India

Abstract

Palliative care is an emerging discipline worldwide which focuses on improving the quality of life of patients with chronic life threatening condition like cancer. Globally, palliative care is sparsely distributed in developing countries including India where the need is immense. While there is extensive coverage of this issue in palliative care literature, there is limited coverage in public health literature, which suggests that the challenges of palliative care have not been generally recognized as a priority in public health. The present article will embark upon various challenges and solutions for implementing palliative care in the country. By considering this discipline in the field of public health literature, it is hoped to raise awareness and stimulate thoughts among public health professionals and health policy makers. In addition to this, a model based on preexisting research has been proposed, that will facilitate palliative care services to be delivered through the existing health care system, which will not only be accessible to the needy in remote parts of the country, but also at a cost the community and country can afford.

Introduction

Today India is experiencing an epidemiological transition from the high burden of infectious diseases to an increasing incidence of chronic life threatening diseases; with cancer being the third most common cause of morbidity and mortality [1]. While in developed countries more than half of all cancer deaths occur in individuals greater than 70 years of age, in India most deaths occurs at less than 70 years of age [2]. This paradox could be due to multiple factors like infection, tobacco use and poor access to screening facility and early stage case finding services. Poor accessibility and availability of an organized and regulated health care systems in the country compounds this effect leading to poor utilization of the service with resultant delayed diagnosis and treatment. The International Agency for Research on Cancer GLOBOCAN [2]. project has predicted that India's cancer burden will nearly double in the next 20 years, from slightly over a million new cases in 2012 to more than 1.7 million by 2035. These projections indicate that the absolute number of cancer deaths will also rise from about 680 000 to 1.2 million in the same period. Thus greater than 70% of this population will suffer from distressing symptom often unaddressed and under treated. India ranks at the bottom of the Quality of Death Index. The Quality of Death Index, commissioned by the Lien Foundation [3], Singapore, measures the quality of Palliative Care in 80 countries around the world, using 20 quantitative and qualitative indicators across five categories: the Palliative and Healthcare environment, human resources, the affordability of care, the quality of care and the

level of community engagement. While the UK and the US rank 1st and 9th respectively; India ranks 67th. Kerala is often cited as a "beacon of hope", contributing to two-thirds of India's palliative care services, being the home of only 3% of India's population [4].

Cancer is a social problem affecting both the patients and family threatening their social stability. This warrants a multidisciplinary support system to navigate patients and family through the problem which is more complex than just physical needs. Patients with advanced cancer at the terminal stage of the disease suffer from a multitude of physical and psychosocial problems which when left unaddressed results in a debilitating quality of life [5]. Among the problems pain is the most distressing symptoms followed by anorexia-cachexia, fatigue, anxiety and depression [6]. Palliative care addresses these problems of the patients providing a holistic healing through a multidisciplinary team approach. The fact sheet on palliative care developed by the National Summit on Non Communicable Diseases initiated by the Ministry of Health and Family Welfare and the WHO country office in 2011, states that more than 98% of the needy in India do not have access to palliative care [7]. This article will discuss the challenges of implementing palliative care in the community and development of a community based model attuned the health care delivery system in the country.

Challenges for developing palliative care in India

Distribution of palliative care services: Currently, there are over 908 Palliative Care centers in India, which are accessible

to a mere 1% of a population of over 1.3 billion people [4]. This disparity in the need and availability of service, poor accessibility to the existing centres providing palliative care and poor societal awareness leads to large majority of the population to live in poor quality of life until end of life. Community based palliative care models have been successfully tested over years making palliative care available to patients at their door step. Palliative care needs must be fulfilled within the ambit of the social, cultural and economic background. This will ensure palliative care reaches to two thirds of the terminally ill patients. Various models have been adopted by different regions in the country attuned to the social background, with personal ideologies and experience acting as a driving force.

One of the WHO demonstration projects 'Neighboring Network in Palliative Care' was developed in Kerala in 2001 to empower the local community to supplement the work of the doctor and nurse in providing palliative care to the patients at the door step. This exemplifies a pragmatic model illustrating collaboration between the government and NGO sector [8]. The community includes a group of volunteers who work in close collaboration with doctors and nurses in providing most needed emotional and spiritual support, nursing care, nutrition and empowering the family in caring for the patients. This model has succeeded in making palliative care a people's movement and transferring the responsibility and ownership to the community. This is also an alternative to the present over-medicalised, over-specialised, institutionalised, and in the long run unaffordable care of the dying. The only challenge in implementing this model is its replicability in other regions of the country as this depends on the earnest efforts by the interested volunteers in the community. The other challenge includes clarity about the borders identified for the volunteer intervention.

The Can-support domiciliary palliative care in Delhi started in 1997 runs day care and home visits to terminally ill by professionals comprising doctors and nurses. The volunteers obtain resources in the form of funds, free medicines, food ration and sponsorship for children's education. They have 11 home care teams, each consisting of doctors, nurses, and counselors trained in palliative care, to cover the different parts of Delhi and National Capital Regions. They provide home visits to approximately 80–85 patients with advanced cancer every week [9]. Can Support with its expansive and holistic coverage proves to be a good model for community based care. The major challenge in implementing this model is its sustainability and adaptability to other regions of the country due to its intense monetary need for sustenance.

In the year 2010, Maharashtra started the community based palliative care to serve the rural population in the state. This was a collaborative project between National Health mission and Tata Memorial Center, Mumbai. The program aimed at utilizing the existing health system to provide palliative care. The ASHA (Accredited social health activist) workers in the community were trained in identifying patients with palliative care needs. The ASHA acted as an important link between the community and the physician in the primary health centers. The ASHA and the auxiliary nurse midwifery provided regular follow up to

the patients, notified to the physician and organized for their transport to the primary health centers. This is a robust and a cost effective model as this utilizes the existing health care system. The well-meaning community volunteers (ASHA) and the physician could in collaboration help the terminally ill in the community. But this is not without challenges. The physician in the primary health centers, though well meaning, are inundated with many government run programs that obviously take precedence over palliative care. They spend large proportion of their time in preparing documents and reports for the various programs, thus leaving them with very little time for patient counseling and care.

Economics of care

Although India ranks third largest economy in terms of gross national income [10], however this has not transpired into improved health care indicators. Health care access in India is such that 70% of healthcare expenditure is spent out of pocket of which 70% is spent on medicines alone leading to indebtedness [11]. The government expenditure on healthcare is only 1.04% of GDP which is only 4% of the total expenditure [10].

A very large proportion of the population in most regions of the country still does not enjoy any social protection or is covered only very partially. Informal economy workers are not covered by social security for a variety of reasons. One is the extreme difficulty of collecting contributions from them or, as the case may be, from their employers. Another problem is that many of these workers are unable to contribute a relatively high percentage of their incomes to financing social security benefits and are unwilling to do so when these benefits do not meet their priority needs. Their most immediate priorities tend to include health care, in particular where structural adjustment measures have reduced access to free services. They feel a lesser need for pensions, for example, as to many of them old age appears very remote and the idea of retirement perhaps unreal.

A number of publicly financed health insurance schemes were introduced to improve access to hospitalization services and reduce the burden of medical expense on the family. This was introduced in eight states of the country [10]. The results were appalling as it was found that nearly half of the previously enrolled households did not continue to avail the service as it had a higher catastrophic inpatient expenditure especially in the urban areas [12]. The scheme also does not include outpatient care which cumulates to 60% cost of medical expenditure to family [13].

Need and availability of morphine

Opioids are the cornerstones for the management of moderate to severe pain. As per the "Millennium Development Goal 8 (target 17), in cooperation with pharmaceutical companies, there should be access to affordable, essential drugs in developing countries." In case of opioid analgesics, we are nowhere near the target as compared to any other class of medicines. Morphine is the most common opioid in use. The drug as such is inexpensive costing only 1cent US for 10 mg of

the drug which makes morphine a cost effective medication for moderate to severe pain. Statistics show that 83% of the population in India, lives in areas with low to non-existent access to morphine [14]. About 60–65% of patients with advanced cancer will have pain due to direct tumor involvement. The morphine consumption for India is alarmingly low, and almost nonexistent in some parts of the country (per capita consumption of Morphine was 0.13 as of 2006 with Adequacy of morphine consumption of 0.0008 almost equivalent to the Burkina Faso in Sub-Saharan Africa [15].

The NDPS act was amended in the year 2014 in order to ensure easy and uniform availability of opioids for pain and symptom control to the needy in the population [16]. The amendments include:

- The power of amendment will be vested with the central government; ensuring uniformity for all states and union territories
- A single order instead of the existing practice of four to five licenses would enable them as recognized medical institution to procure and dispense essential opioids like morphine
- Licensing will be required only from drug controller of the state rather than the current practice of multiple agencies; thereby, simplifying and encouraging more and more institutions to dispense morphine to patients in severe pain.

Only states of Kerala, Karnataka, Tamil Nadu and Delhi have shown improvement to access to opioids. It is the onus of the other state government and local palliative care providers to ensure implementation of the amended NDPS rules and to generate awareness of the newly amended act amongst healthcare providers, pharmacists and the general public [17].

Way forward

Considering the vast expanse of the country and the disparate distribution of health services and health system hierarchy (between rural and urban area), it is difficult to develop a unified model of care across the country. Also the distance to cover to reach health center and cost of travel and treatment precludes utilization of service by the community. Integration of services into existing health systems seems to be a feasible solution considering the immense need for palliative care in the community. Thus a model of care that empowers health care personnel right from the community to tertiary centres will be a practical approach to the present problem.

Learning from other community models, an 'integrated model of care' (Figure 1) with ongoing care provided by primary care physicians with expert inputs from specialist palliative care physicians seems a feasible approach. Primary palliative care in the community can be provided by general practitioners, family physicians, public health physicians in the outpatient clinics or through domiciliary care after obtaining mandatory training in basic palliative care. The training will include both theory and practical work and will encompass identification of

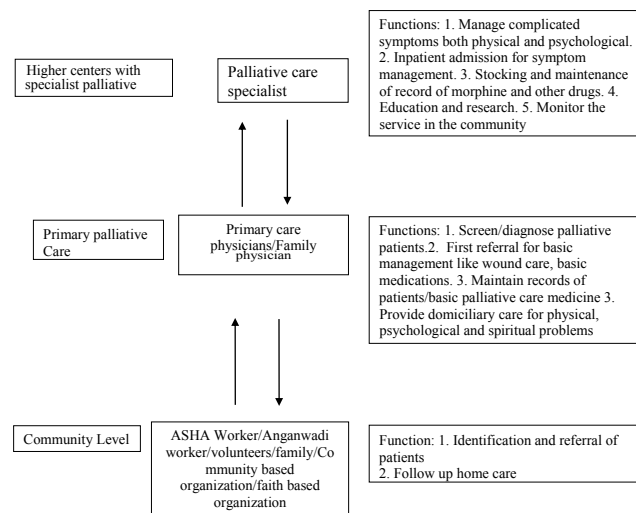


Figure 1: Algorithm depicting the flow of patients.

patients with chronic life threatening illnesses, screening of symptoms, appropriate management and referral to specialist, communication skills and documentation and record keeping. The physician provides the first aid for emergencies and refers the patients to the specialist palliative care physician for more complex cases or cases demanding inpatient care. The specialist palliative care physician will provide care for more complex physical and psychological symptoms and admits patients who need inpatient care. The physician will also provide medical advice and education support to primary care physicians and volunteers in the community. Additionally, the specialist will be responsible for providing managerial input on the running of the program on a timely basis and amend the program as appropriate.

Conclusion

Despite the efforts by the palliative care providers in the country, palliative care delivery in India is far behind the globe. Although the National Palliative Care policy spells out the objectives of covering all aspects including education, attitudinal shift, behavioural change in the community and palliative care standards, they have yet to be implemented. Though various models have been tested over time, their implementation will wholly depend on the socio-cultural background. This also needs tremendous political support and also the willingness of the local community leaders to implement the program. A simple yet a robust model were depicted in Figure 1. Community sensitization must happen parallel to empowering the primary care physicians as the generation of the demand for health care and its fulfillment can happen if only could both community and health care system work together as a team.

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